

Written Testimony of
Peter Nichols
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Joint Committee on Public Health

SB 654 An Act Concerning the Availability of Prescribed Antiepileptic Drugs

Thank you Chairman Handley, Chairman Sayers and members of the Public Health Committee for this forum today. I hope I can shed a bit of light on what is in my belief a simple but necessary safe guard for persons with epilepsy who rely on their medications to control their epilepsy.

My name is Pete Nichols. I am here today because my wife has had epilepsy since birth and is currently controlled by a cocktail of antiepileptic medications. When a person is controlled, it means that you have to visit your doctor and get your blood levels taken regularly. This has to be done because as your body ages or goes through other changes, your dosage needs to be adjusted so the medication stays at a therapeutic level. There is a careful regiment to follow when your doctor gives you a prescription, and you have the responsibility to take the medication as prescribed, otherwise what good is it?

Now I can't speak for everyone but I can speak for my wife, Susan. She has to take a battery of pills each morning, at lunch and at dinner time so we have a system. She uses a daily pill box with the days of the week etched on top of little doors to tiny compartments that contain the right dose for that particular time of day. She also has an alarm on her watch, cell phone and back up timer all set as redundant reminder systems to keep her on track with the meds. I tell you this to give you a peek into our world. We must exercise extreme caution because the meds only work if we get them into her system by a certain time. They have a half life too so on days that are stressful, they break down sooner and on other days, they may break down faster. It all depends on how quickly the body processes and breaks down the components of the medication. Other things that we all must do to stay healthy can also affect the medication levels, such as getting enough sleep taking vitamins, eating right, and exercising. For a person with epilepsy who depends on medication to avoid a seizure, all of these things are critical.

You know the medication is really a miracle in a bottle. Because of it, my wife Susan is a professional with a highly responsible position. She has a Masters Degree, has published work at the Library of Congress, and is also an award winning racing sailor. In short, she is living a good and active life -- thanks in no small part to the research and development of some of the best pharmaceuticals on the market today. But these wonder drugs do not come cheap. Last year the cost was over 12,000.00 dollars. So there is no doubt that any person with a chronic need for medication will look for ways to handle the out of pocket cost of these meds and will want to use generics whenever possible. Just the thought that a generic med you currently take with success -- one that is made by say Teva can be switched to the same compound made by Mckesson without your knowledge or the knowledge of your doctor is shocking.

Earlier I described the daily routine we undertake to make sure Susan gets the meds in the correct dose at the correct time and the blood tests to track the medication already in her system. All of that points to how closely we must watch this. If a new manufacturer is unknowingly introduced into the picture, the results can be disastrous.

By now you may have heard that generic drugs can vary as much as 20 percent between manufacturers. This is a cold hard fact. If there is just say a 5 percent variance in a generic anti-epileptic drug and you need that drug say in 3 daily doses, that is 5 per cent less or more than you need. And over time, anyone can see that these inconsistencies can create a huge problem. Too much or too little medications can result in seizures. And since you were taking what you thought was the correct dose it may take many months to track it down. In the meantime, you are jeopardizing the lives of yourself and everyone else and you are having seizures.

I have heard that Pharmacists are concerned that we may have to wait at the prescription counter. First of all, we cannot wait until my wife runs out of medication before calling the pharmacy. Second, I am here to tell you that I will decide what is convenient for me. We would prefer to be informed about any changes to the delicate balance of medications my wife takes each day even if we may have to wait.

We need a fix now! We need you to do something that is actually within your power. All of you senators and representatives in this room today can make this problem history. So please think about this for a moment – It is after all a simple thing we are asking, and it is the right thing to do. It is after all the human thing to do. I need, she needs, and we all need your support of this bill. It is hard enough having epilepsy without having to worry about your medications being switched without your knowledge.

Thank you for listening!